

The European ME Alliance welcomes the progress report on WHO Europe's **European regional action framework for behavioural and cultural insights for equitable health, 2022–2027**.

We applaud WHO Europe's work on addressing these important issues.

Behavioural and cultural norms often look at those of patients, but moving forward, need to address actions of all stakeholders that negatively affect the equitable health of patients. For decades, people with illnesses with no diagnostic biomarkers, such as Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS), have suffered deleterious treatment based on lack of knowledge and misinformation about the disease.

For example, somehow it has become culturally and morally acceptable for decision-makers, without expertise in ME/CS, to tell people suffering from its severely disabling symptoms that they are healthy, based on disbelief due to misinformation, despite the wealth of published information that it is a physical illness and its recognition by WHO as a neurological condition since 1969.

It is long overdue to address the trauma experienced by ME/CFS patients when their family members are told not to help them because otherwise they will never recover from their wrong beliefs, which leads sufferers to feel abandoned and overexert themselves and worsen their symptoms. The overexertion leads to an impairment of their energy production, which in turn further reduces their physical and mental capacity to function. It places them among the most disadvantaged who are not able to defend themselves.

Our recent Pan-European Patient Survey of over 11,000 patients confirms that ME/CFS is severe even in its mildest form, leaving most sufferers unable to work. Many are so disabled they must choose between daily activities like eating or brushing their teeth. Some days they remain in bed with only enough energy to keep their basic bodily functions working. Many experience brain fog, sensitivity to light, sound, and smells, and need to remain within the protective environment of their homes and bedrooms. Many are diagnosed after 7-12 years, demonstrating a wide variation in how people with ME in Europe are treated with no standard approaches and with late diagnosis leading to the risk of poorer outcomes.

Because their symptoms are seemingly 'invisible', sufferers are disbelieved and stigmatized as 'lazy' and 'malingerers' who do not want to work, leaving them excluded from receiving financial support and social services.

The European Union's 2020 ME/CFS Resolution estimated 2 million people in Europe and 24 million worldwide are diagnosed with ME/CFS. The Resolution notes this is considered 10% of the actual number because the majority of ME/CFS patients do not receive a diagnosis. Do our cultural beliefs really lead us to think that millions of people worldwide are lying about their symptoms and choosing to live in such sub-human conditions for years and decades?

There is an urgent need to change our culture and behaviours to BELIEVE people with ME/CFS symptoms and to urgently provide them with the assistance they desperately need and deserve, including legal protection of their basic human rights.

This can be done within a comprehensive and well-funded European Strategy on ME/CFS, working towards binding recommendations on how to treat people with diseases for which researchers have not yet discovered diagnostic biomarkers – and to prevent creating gaps in our culture where institutions, governments, the media and society in general accept explanations of

laziness and malingering in regard to severely disabled people, who as a result are stigmatized, causing greater disability levels.

The European ME Alliance stands ready with the expertise of its international network of patient organizations, researchers and clinicians to support a European Strategy on ME/CFS.

\* <https://www.europeanmealliance.org>

\*\* <https://www.europeanmealliance.org/emeasurveyeu.shtml>

\*\*\* <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020IP0140>